Governor's Commission on Mental Retardation

How Are Providers of Family Support Services Changing In an Era of Individual and Family Empowerment?

A Staff Report

How Are Providers of Family Support Services Changing In an Era of Individual and Family Empowerment?

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

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Volume 2, 1, July 1998
The Commonwealth of Massachusetts

HOW ARE PROVIDERS OF FAMILY SUPPORT SERVICES CHANGING IN AN ERA OF INDIVIDUAL AND FAMILY EMPOWERMENT?

Introduction

The provision of services and supports designed to meet the needs of the entire family and not just those of the individual with a disability is a relatively new development. Slowly, with guidance and, at times, pressure from parents, states and community organizations are beginning to recognize their responsibilities to families and are increasing the supports and services they provide. It is to the credit of grass roots lobbying efforts by parents that the concept of family support is beginning to be accepted at both state and national levels (Smith, Card, & McKaig, 1987). In 1972, Pennsylvania became the first state to initiate a formal family support project. In *Family Support Services in the United States: An End of Decade Status Report* (Knoll et al., 1990), the Human Services Research Institute found that all but a handful of states now provide some form of support to families who have children with developmental disabilities.

In recent years, the Commonwealth of Massachusetts has begun expanding family support programs. Total spending for family support activities nearly doubled between 1988 and 1996, from $18 million to $34.2 million. In the past three years the number of families served has grown from 10,384 in 1993 to 14,448 in 1996.

The Commonwealth has entered a new era in which families and individuals with disabilities are able to exercise greater control over their destinies and have more opportunities to direct and manage their services and supports. As noted in the Massachusetts Department of Mental Retardation Family Support Guidelines, "the primary goal of family support is to provide a wide array of options to families of people with disabilities that enable them to stay together and to be welcomed, contributing members in their communities. Successful family support programs recognize that families are the experts regarding the strengths, competencies, capacities and needs of their family members and are in the best position to know what will help them provide for a family member with a disability."

In order to evaluate the change in family support programs, the staff of the Governor's Commission on Mental Retardation in conjunction with the Association of Developmental Disabilities Providers Family Support Committee examined how family support services have evolved over the past several years. This report will describe the development of this study and its results.

Overview

The philosophy behind family support is that families of people with disabilities know their own needs and those of their family members. For this reason, the types of goods and services available under family support are usually quite broad in scope. The most typical forms of family support include: 1) family leadership and development, 2) education and training, 3) networking and support groups, 4) brokerage, 5) supports and services for community participation, 6) outreach and education to community members and organizations, 7) stipend and other flexible financial assistance mechanisms, 8) respite.

An examination of the service delivery system for family support requires an understanding of how family support services are currently delivered in Massachusetts. The Department of Mental Retardation (DMR) administers the family support system through five regional offices and 24 area offices. Each region has a children's coordinator responsible for providing information, assistance, and referral to family support providers. Much of the family support system is implemented through provider agencies across the state. According to the DMR Annual Report July 1, 1996-June 30, 1997, there are approximately 320 private provider agencies that contract with the state. Of these 320, 97 providers (30%) have contracts for family and individual support. Presently, about 16,000 families receive assistance through the DMR family support system. According to a survey conducted by the Western Massachusetts Training Consortium and Arc Massachusetts in March 1997, more than 75% of respondents (approximately 405 families responded out of 2,000) were very satisfied with the services and supports they receive.

There is a statewide coalition dedicated to individual and family support. Massachusetts Families Organizing for Change (MFOFC) provides families with opportunities to learn from each other's experiences, a place to give and receive emotional support, and an organizational base to tackle problems at the regional level. Members of MFOFC have proposed legislation to create statewide policy and practice for individual and family support.

Purpose

The developmental disabilities field has undergone enormous change over the past decade in the design and delivery of family support. Since 1995, DMR has increased the number of families who use flexible family support dollars by 50% and has issued a set of guiding principles that articulate standards and expectations that characterize program development efforts statewide.

The cornerstone of an effective family support system is families and their ability to play a leading role in the decision-making process. Such action is consistent with contemporary thought regarding the need to empower families in ways to assure that the system is most responsive to them (Knoll et al., 1990). Family support empowers individuals and their families to speak out for themselves and others, encourages the initiation of ideas, provides choices, and allows families to make decisions about needed supports. The staff of the Massachusetts Governor's Commission on Mental Retardation and the Association of Developmental Disabilities Family Support Sub-committee examined the extent to which agencies have shifted their organizations to promote such family empowerment. The goal of this study was to determine what components have been critical in assisting in the transformation to an empowering organization as well as to identify what barriers prevent agencies from creating a responsive context for family support.

Methodology

In determining how to best obtain information from providers, a series of meetings was conducted with family support program directors and DMR regional children's coordinators. A four-page survey instrument consisting of 29 questions was designed to collect information on fundamental program features as well as topics related to program administration, family empowerment and systemic changes in the delivery of family supports [see Appendix 1]. In addition, providers were asked to identify administrative barriers or obstacles that prevent the delivery of services and supports.

The majority of questions were designed in a closed format that required respondents to choose from response options. Five questions were open-ended, inviting written comment.

Individual and Family Support
Program Code: 3175
This service provides supports to individuals who are living in independent or semi-independent situations and to families who have living with them adult children (over the age of 18) who have mental retardation or minor children with developmental disabilities.

DMR supplied the Governor's Commission on Mental Retardation with a computerized listing of all provider agencies that have a program code for individual and family support. During February and March 1998, all executive directors of individual and family support agencies were mailed the survey tool. A follow-up letter was sent to all non-respondents. In addition, a fax was sent by the executive director of the Association of Developmental Disabilities Providers encouraging all family support provider agencies to participate in the survey.

Results

A total of 97 surveys were mailed, and responses were collected from 58 agencies (60%). In addition, 6 surveys were returned as non-applicable. The findings presented in this paper will be discussed in three major sections.

The first section of the report provides a general profile of the respondents including:

- Development of family support services;
- Location of services;
- Individuals served;
- Waiting list information;
- Fiscal Status;
- Eligibility;
- Selection criteria.

The second part of the report will review benchmarks of systemic change in the development of family support services. The following four indicators: change in structure, technology, behavior, and values and assumptions will be explored and analyzed. The final section of the report will review challenges and obstacles to implementation of a family-governed and family-directed system of supports.

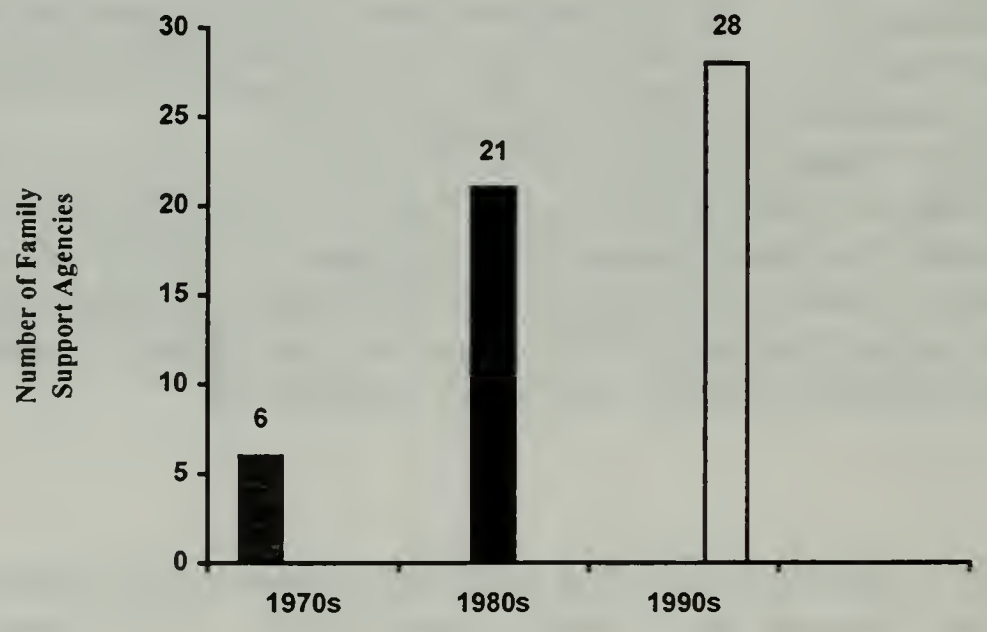
Profile of Respondents

Development of Family Support Services

Agencies were asked to indicate the date they began to provide family support services funded by the Department of Mental Retardation. 55 (95%) agencies responded to this question. Six programs (11%) reported that they started to provide family support services in the 1970s. Twenty-one programs (38%) initiated services in the 1980s, and 28 programs (51%) started in the 1990s [see Table 1].

Table 1

Development of Family Support Services



In 1987 the Department of Mental Retardation established the first Office of Family Support, whose primary objective was to develop an array of services which "made it possible for more families to stay together" (1988, House 1). Given the elevated status of family support in 1987, it is not surprising to see the volume of programs established in the late 1980s and early 1990s.

The Massachusetts Department of Mental Health was **created in 1919.** It was established to care for two populations: those with mental illness and those with mental retardation. The Massachusetts Department of Mental Retardation was **created in 1987.**

Location of Services

DMR administers five regional offices across the Commonwealth. Services and supports are provided in local offices that operate within each region. DMR has made a commitment to strengthening the area office structure in order to promote more local access to DMR services (1993, DMR Unified Service System Policy). Forty-six agencies (79%) indicated that they provide services within one geographic DMR region. Twelve agencies (21%) stated that they provide services within several DMR regions.

Table 2
Location of Provider Agencies

Region	# of Agencies Who Provide Services within One Region	% of Agencies who Responded to Survey
West	12	21%
Central	5	9%
Northeast	6	10%
Southeast	11	19%
Metro	12	21%

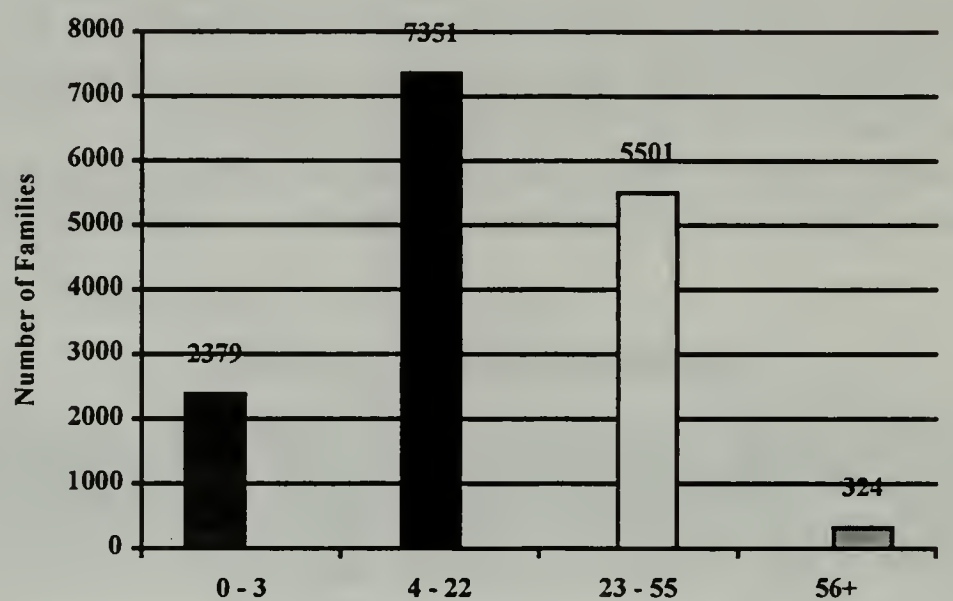
*(These figures do not include 12 agencies that provide services within several regions.)

Individuals Served

Forty-eight agencies reported that they served a total of 15,555 families in FY'97. Agency respondents indicated that 2,379 (15%) families received services for family members who were infants 0-3 years old. Among those with family members between the ages of 4-22, 7,351 (47%) families received services. 5,501 (35%) families received

services for family members between the ages of 23-55, and 324 (2%) families received family support for family members 56+ years old. These numbers reflect the Commonwealth's commitment to support children in their home communities.

Table 3
Families Served



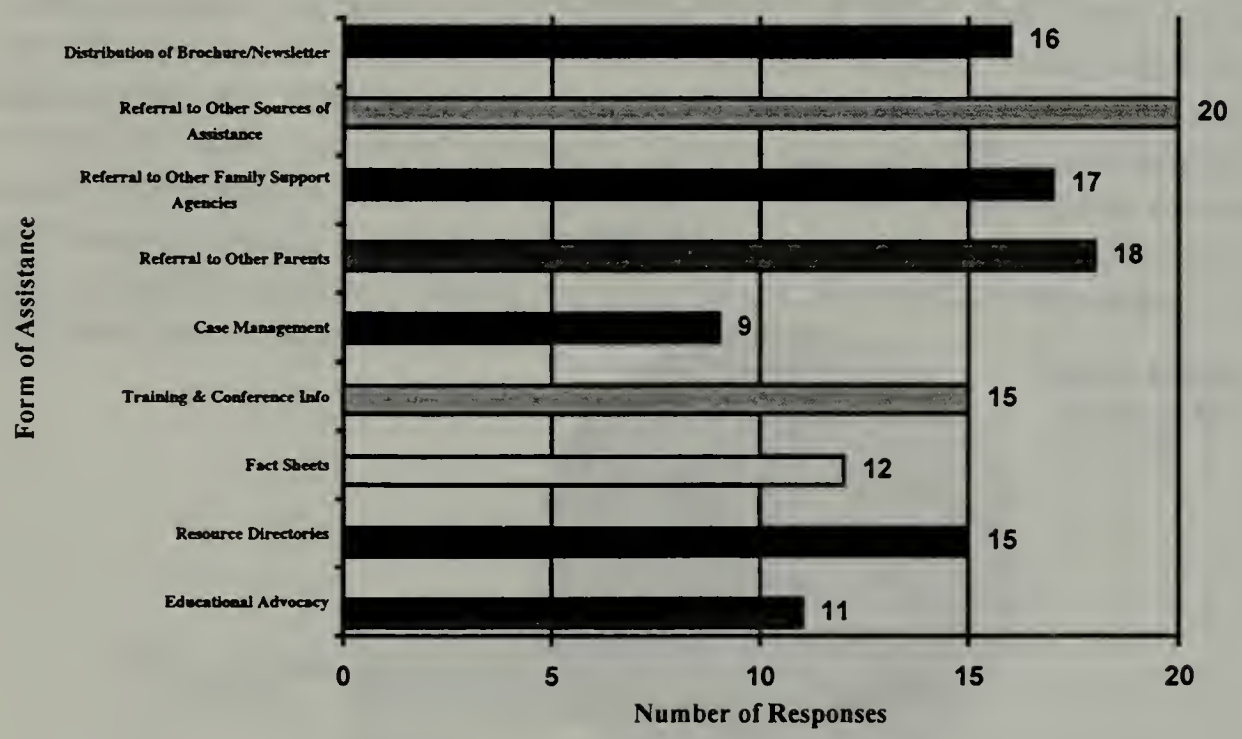
Waiting List Information

Fifty-five agencies (95%) provided information regarding waiting lists for family support services. Twenty-three agencies (42%) maintain a waiting list for family support and 32 agencies (58%) do not. Of the 23 agencies that maintain waiting lists, numbers of individuals waiting for services are reported in four categories. Sixteen agencies reported an average of 1-10 families waiting for services each month. Three agencies reported an average of between 11 and 20 individuals. Three agencies reported an average of between 60-80 individuals, and one agency reported an average of 100+ individuals waiting for services each month.

In addition, 21 out of 23 agencies indicated that they provided various types of assistance to families who are waiting for services. Table 4 illustrates the types of supports provided.

Table 4

Services Received by Famlies on Waiting Lists



In Massachusetts, DMR maintains a waiting list of individuals eligible for and in need of DMR services. This information is contained in a computerized database that has been maintained consistently since FY'92. The waiting list identifies only those individuals who are waiting for residential and/or day services. DMR has acknowledged that 373 individuals who are listed on the waiting list for residential and day services are also waiting for family support. DMR estimates that there are 1,731 individuals living at home and waiting for some type of family support (Report on the DMR Waiting List for Services, 1997).

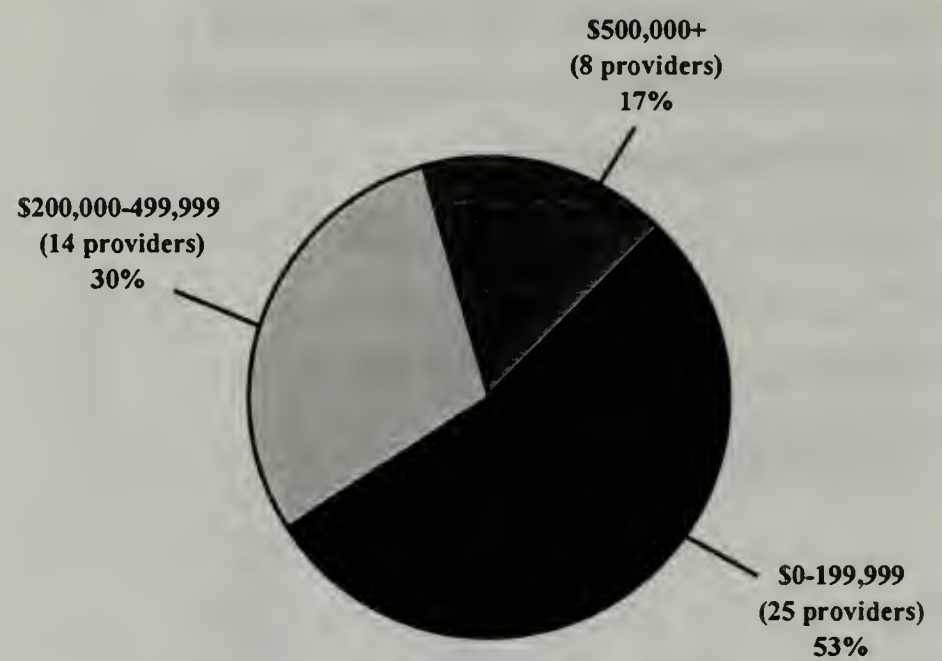
Fiscal Status of Agencies

Agencies were asked to indicate the total FY'97 annual budget for family support services. Forty-seven of the 58 agencies provided financial information on the survey form, and the annual budget allocations varied considerably. Eleven agencies (23%) reported

allocations under $100,000, while 4 agencies (9%) reported family support allocations between $1,000,000- $4,000,000. Table 5 illustrates that the largest percentage of agencies (53%, n=25) have budget allocations under $200,000.

Table 5

FY'97 Family Support Budgets



Eligibility

Eligibility for family support services is tied to the diagnostic condition experienced by the family member with a disability. Families may receive family supports if they have children who meet the federal definition of developmental disability. For support services to families with an adult, that person must meet the criteria for mental retardation based on the American Association on Mental Retardation (1992) definition.

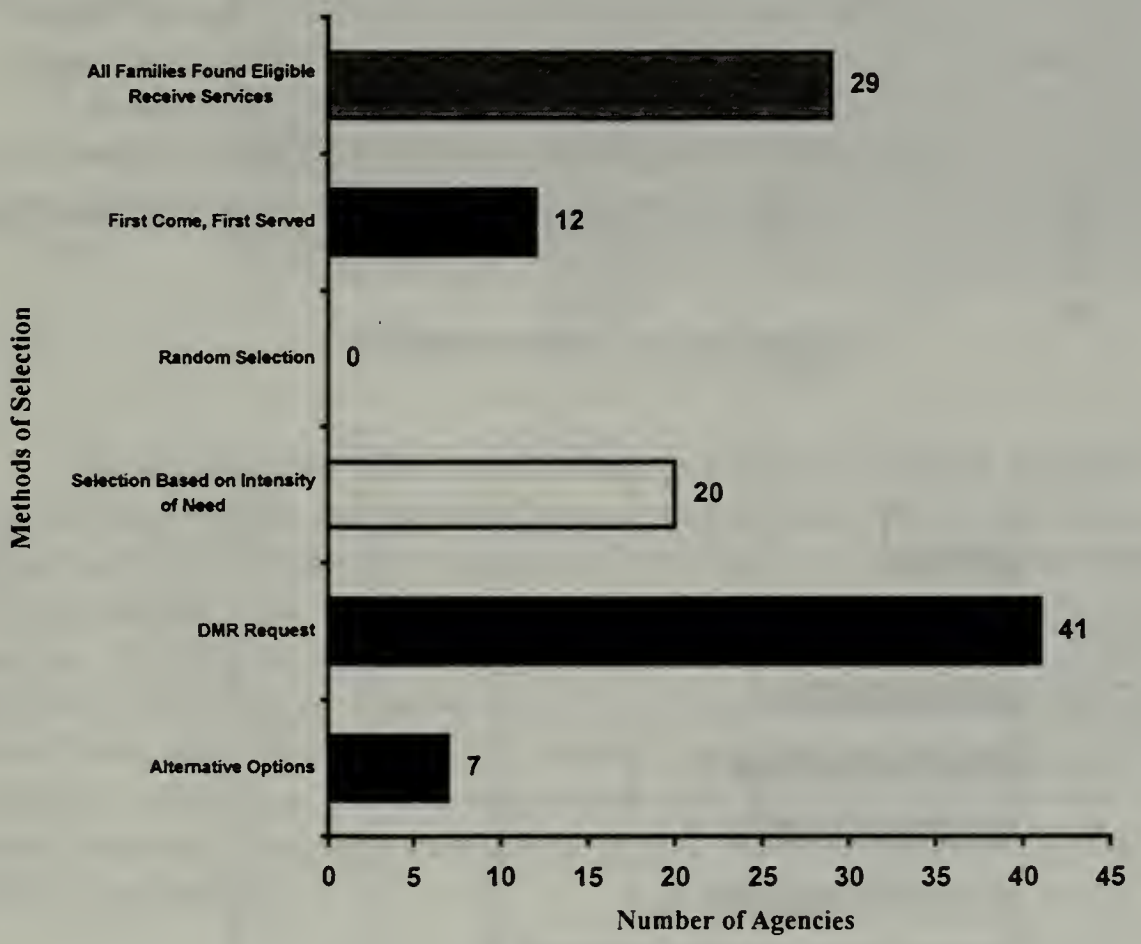
Agencies were asked to identify who is responsible for determining eligibility for family support services. Forty-four agencies (76%) listed the DMR Area Director/Assistant Area Director as the primary "gatekeeper" to screen prospective applicants. This response complements the DMR Family Support Guidelines and DMR eligibility criteria that stipulate "responsibility for eligibility rests with the DMR area director." In addition, 17 agencies (29%) reported that an evaluation team is responsible for determining eligibility. Family support directors/family support staff were identified as part of the evaluation team.

Selection Criteria

Family support programs are often confronted with a difficult administrative issue: how to decide what families to serve given that demand usually exceeds available resources. Thus, a critical dimension of family support programs is the selection criteria used to determine whom among those eligible will actually be served. Twenty-six agencies (45%) use more than one approach. As illustrated by Table 6, 41 (71%) agencies indicated that "DMR Request" is the criterion most frequently utilized. Twenty-nine agencies (50%) indicated that any families who are found eligible receive services. Twelve agencies (21%) use a "first come, first serve" approach. Twenty agencies (34%) use a strategy based on an assessment of family needs, and seven agencies (12%) used alternative measures such as the development of a Request for Proposal (RFP) committee review process and subcommittee review by a family support council. None of the respondents use random selection (lottery) as a strategy.

Table 6

Criteria Used to Select Families



The next section of the report will examine benchmarks of systemic change in the delivery of family support services. Thomas Bennett (1962) described four types of change that are helpful in assessing an organization's awareness of and commitment to change:

Change in structure, technology, behavior, and values and assumptions. The survey asked providers to respond to several questions about these critical areas of change. Each of these categories will be examined separately.

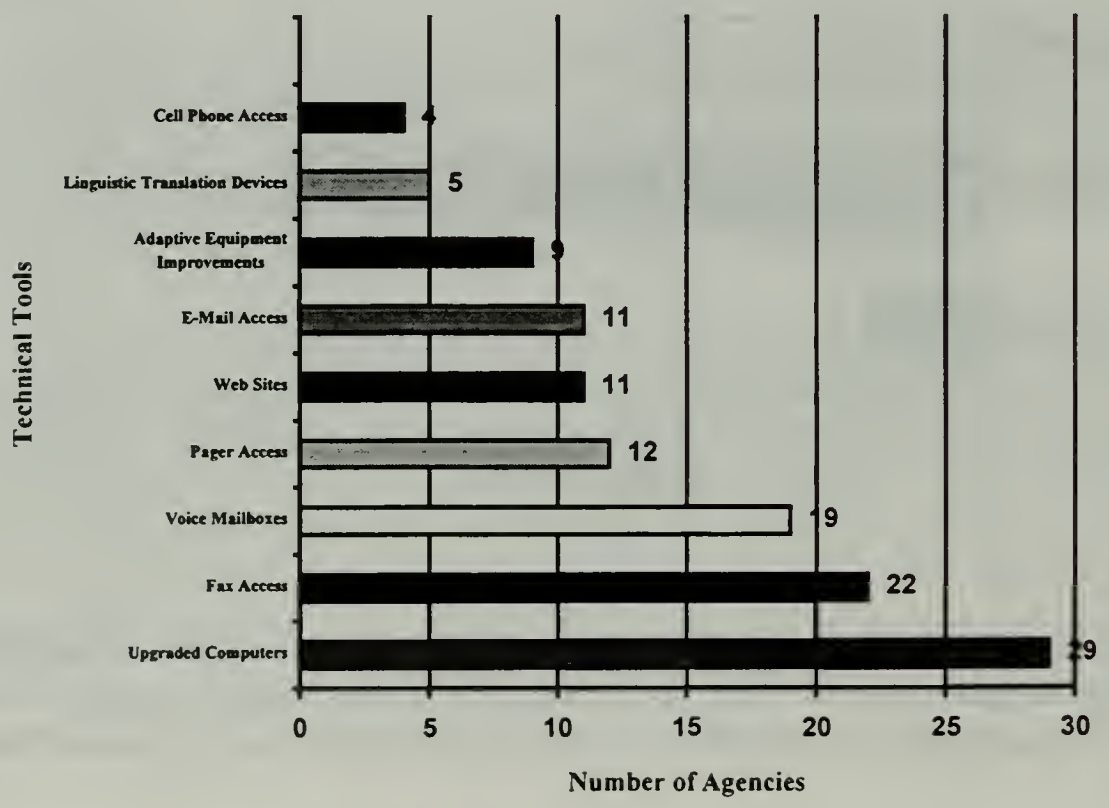
Change in Structure

A change in the structure of an organization is defined as a reorganization of the existing people or program elements. A critical program element of family support is the range of services available to families. Agencies were asked to examine the range of supports provided or paid for in 1992 and 1997. Survey results indicate that agencies now offer an extensive array of supports. Thirty-three respondents (57%) reported that service options available in 1992 consisted of five major categories: information and referral, recruitment/training of respite providers, respite (in-home and out of home), case management and behavioral management. In 1997, virtually every agency indicated that all twenty-nine options listed were now available to families [see Appendix 1, Question 11].

Change in Technology

A change in technology is described as an "adaptation" or modernization of the way to do things. These changes can be capital or physical in nature. Agencies were asked to indicate if any program modifications or technical tools were applied to family support programs. Table 7 reveals that significant improvements and modifications have been completed including: 27 agencies (82%) have upgraded and improved computers, 22 agencies (67%) provide fax access for families, 19 agencies (58%) installed voice mailboxes, and 12 agencies (36%) purchased pagers so that families have 24-hour access to staff.

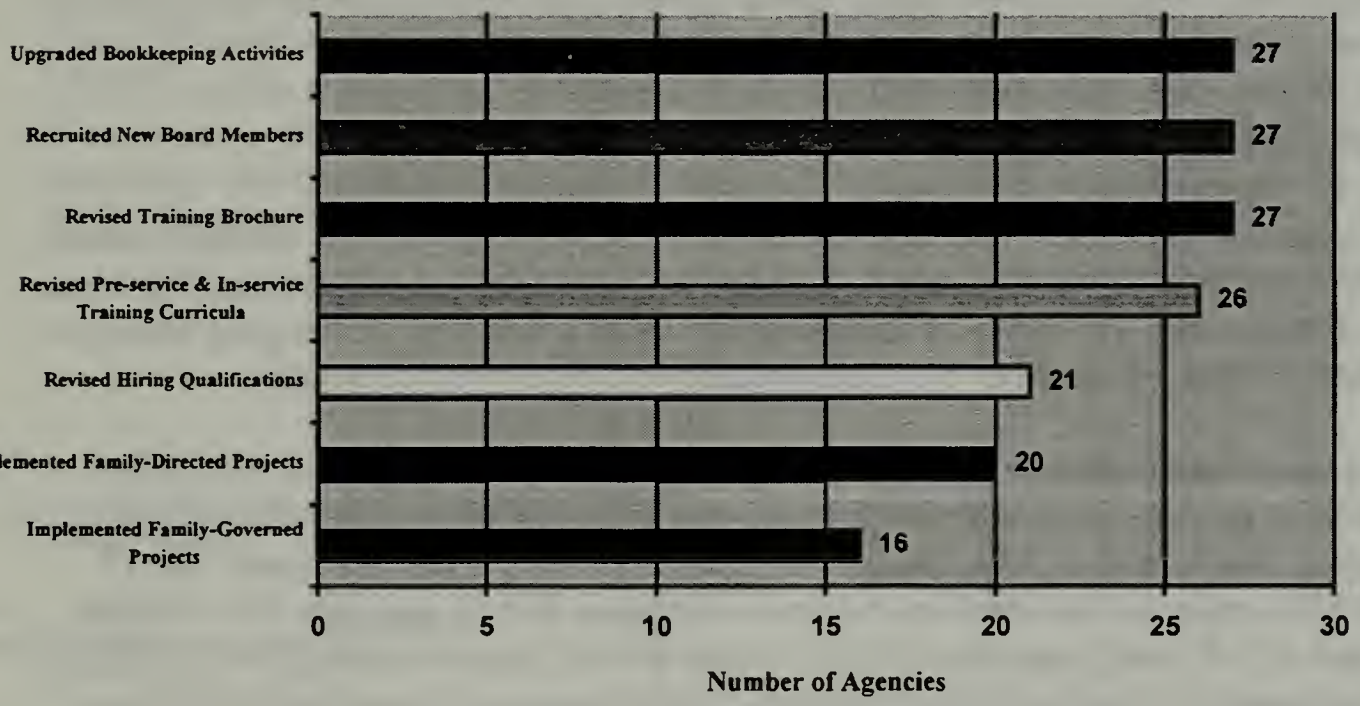
Table 7
Technological Improvements



Change in Behavior

A change in behavior is defined as a change in how things are done in the organization. Agencies were asked about organizational change in several questions. Agencies were initially asked to report on the changes in organizational practices for family support services. As illustrated in Table 8, agencies have made numerous changes in administrative practices including: 27 agencies (82%) have recruited new board members, 27 agencies (82%) have revised program brochures, and 26 agencies (79%) have revised pre-service and in-service training curricula within the last five years.

Table 8
Organizational Practices



The second area of behavioral change relates to funding. Agencies were asked to indicate what funding mechanisms have changed since 1992 in the delivery of family support services. Twenty-five agencies (76%) indicated that the agency "managed" all funding procedures in 1992. Seventeen agencies (52%) handled reimbursements with receipts, 14 (42%) provided direct payments to other agencies upon family request, and 9 agencies (27%) utilized stipends. In 1997, 25 agencies (76%) reported that they employ all four of these identified funding mechanisms in order to purchase family supports (see Appendix 1, Question 16). The largest indicator of change was reported in the category labeled stipends; there has been a 49% increase in the number of providers using this financial mechanism.

The next area of concern focuses on the mechanisms established to involve family members in guiding program decisions and activities. Agencies were asked to indicate what programmatic activities have changed to include families. Twenty-five agencies (76%) out of 33 indicated that the largest areas of change have occurred in two categories. First, families now choose the person who will actually provide the supports. In 1992, 10 out of 25 agencies did not allow families this option, whereas in 1997, all 25 agencies

permitted families to choose their support person. Secondly, families currently have a say in how their resources are used. In 1992, 7 out of 25 agencies did not allow families to direct their own resources, whereas in 1997, all 25 agencies indicated that this is an acceptable and necessary part of family support services.

The final issue pertaining to behavioral change in family support organizations concerns mechanisms that involve family members in policymaking, program development, implementation, and revision. Forty-four agencies (76%) reported that they include families in a variety of planning activities and 10 agencies (17%) indicated that families are not included in policymaking and program development activities. Of the 44 agencies who reported that families are integral to program development, 60% indicated that family members attend meetings that pertain to overall operations of the program, 51% include families in developing the menu of service options available, and 17% invite families to advise program development efforts through participation on boards or advisory committees.

Change in Values and Assumptions

Changes in values and assumptions are the most profound level of change because they involve a shift in values or a renewed understanding of the operational ramifications of values already held. This level of change brings about a new way of thinking about the organization's customers and its role in responding to their expressed needs.

Agencies were asked to indicate if the philosophy of family support changed in their agencies over the past five years. Twenty-one agencies (64%) reported that the philosophy of family support has changed dramatically over the past five years and 12 agencies (36%) reported that there have been no changes. The 21 agencies that changed their philosophy of family support described many revised goals and objectives including: a greater emphasis on family-directed supports, flexible resources based on family need, and an array of supports rather than a single service.

Agencies were also asked if families are included in fiscal decisions other than their own individual allocations. Forty-nine agencies (84%) responded to this question. Thirty (61%) indicated that families are not included in fiscal decisions and 19 agencies (39%) indicated that families are included. Agencies that include families in fiscal decisions reported that families participate in family support councils, advise budget development, and often approve out of home respite placements.

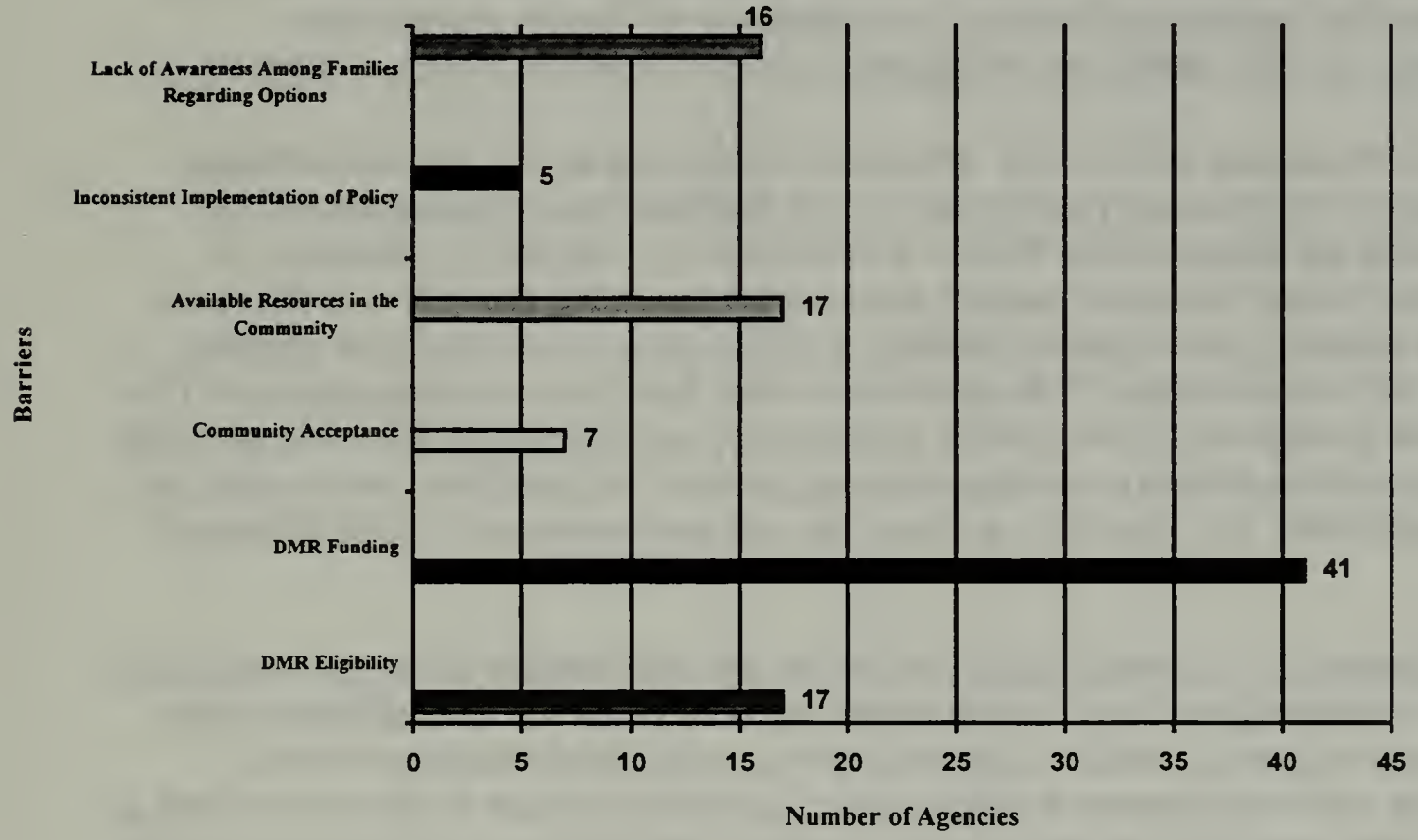
Another indicator of change in values and assumptions is the percentage of families who are now participating in family-directed and family-governed projects. Family-directed projects are defined as families working collaboratively with the Commonwealth to direct how resources will be used to meet consumer need. Family-governed projects are projects where families have primary decision making authority in resource allocation and project direction to provide services and supports. Forty-two respondents provided information on family-directed projects. Out of these 42, 10 agencies (24%) indicated that 100% of families are participating in family-directed activities and 20 agencies (48%)

indicated that 0-10% of their families participate in family-directed projects. Forty respondents provided information on family-governed activities. Out of these 40 agencies, 8 agencies (20%) reported that 100% of families are involved in family-governed projects and 23 agencies (58%) reported that 0-20% of families participate in family-governed projects. Many agencies articulated the need for increased training and technical assistance prior to developing family-governed proposals.

Obstacles to Implementation

The last section of the report will review obstacles to implementation of a family-driven system of supports. There was universal agreement that the Commonwealth has taken many positive steps towards strengthening and improving the service delivery system for family supports. Agencies were also eager to point out that many barriers continue to prevent the system from providing critical family support services to all that request them. Table 9 illustrates that the most frequent response is the need for additional funding from DMR (41 agencies or 71%). Seventeen agencies (29%) cited that DMR eligibility criteria often prevents families from receiving needed services, and 16 agencies (28%) indicated that many families are not aware of the array of services now available under the rubric of family support.

Table 9
Barriers to Implementation



Conclusion

The nation's response to families has shifted dramatically, moving from an historical awareness of disability based in segregation and exclusion to one that favors the integration of people with disabilities into the mainstream of community life (Agosta and Melda, 1994). In 1990, the Commonwealth initiated a fundamental paradigm shift in its approach to supporting people with disabilities. This approach emphasizes family and community, choice and control, and person-centered services. The Massachusetts Department of Mental Retardation Family Support guidelines, issued in July 1996, reflect that fundamental shift in orientation.

The growth of family support over the past decade is laudable. The survey findings reveal that the number of family support programs has increased at a remarkable rate. Within the past twenty years the Commonwealth has expanded family support programs over 400%, and additional resources have been channeled into this service. Forty-seven agencies (81%) reported spending over $20 million in family support services in FY'97. Significantly, the total DMR expenditure for family support in FY'97 is $37 million, 5% of the total budget. Clearly, the Commonwealth needs to research additional financing strategies that will increase the monies available to families if we are to develop a truly comprehensive system of support.

The findings also disclose several interesting and noteworthy facts: (a) a commitment among families to care for children at home; (b) a significant increase in the range of services available to families; (c) development of flexible procurement mechanisms; and (d) a shift in the philosophy to a family-centered system of supports.

Survey findings indicate that agencies are challenged as they attempt to change organizational structures and professional roles to facilitate family empowerment. As Bennett notes, no change is ever "little"-- it is likely to be a big step for someone. A fundamental value of the family support movement is the ability of families to direct and control the resources and supports available. Yet the survey reveals that most agencies (61%) do not include families in fiscal decisions other than their own allocations, and 17% indicate that families are not included in policymaking and program development activities. Resources are often the key to the empowerment process. For families to have control and make good choices, they must have access to the necessary resources to make informed decisions.

Agencies also reported a lack of awareness and experience with family-directed and family-governed projects. The Commonwealth needs to review the level of involvement and participation among families in the various programs. The distinction between involvement and empowerment is often unclear. Parents do not have to become involved at all levels of the program to be empowered, yet the system needs to create access to needed resources, prompt families to make their own choices, and encourage them to participate in a variety of ways.

This study reveals that the Commonwealth has undergone enormous change and significant growth in the development and delivery of family support. It is incumbent upon all stakeholders to support the momentous advancements and refocus their energies on areas that are in need of review. There are many systemic barriers that still need to be addressed. The challenge is to continue to explore strategies and avenues to address system flaws and design a system that is responsive to all families in need of support.

References

Agosta, J. (1992) Evaluating family support services: Two quantitative studies. In V. Bradley, J. Knoll and J. Agosta (Eds.), Emerging issues in family support (pp. 99-150). Washington, DC: American Association on Mental Retardation.

Agosta, J. and Melda, K. (1995) Results of a national survey to update the status of family support programs for children with developmental disabilities. Salem, OR: Human Services Research Institute.

American Association on Mental Retardation (1992). Mental Retardation: Definition, Classification, and Systems of Supports. Washington, DC: American Association on Mental Retardation.

Bennett, T. (1962). The Leader and the Process of Change. New York, NY: Association Press.

Bradley, V. and Knoll, J. (1990). Shifting paradigms in services for persons with developmental disabilities. Cambridge, MA: Human Services Research Institute.

Commonwealth of Massachusetts (1987). House No. 1 The Governor's Budget Recommendation Fiscal Year 1988. Boston, MA.

Knoll, J., Covert, S., Osuch., R., O'Connor, S., Agosta, J., Blaney, B., and Bradley, V. (1990). Family support services in the United States: An end of decade status report (summary report). Cambridge, MA: Human Services Research Institute.

Massachusetts Department of Mental Retardation (1998). Annual Report July 1, 1996-June 30, 1997. Boston, MA.

Massachusetts Department of Mental Retardation (1997). Report on the DMR Waiting List for Services. Boston, MA.

Massachusetts Department of Mental Retardation (1996). Family Support Guidelines. Boston, MA.

Smith, M., Card, F., & McKaig, K. (1987). Caring for the developmentally disabled child at home: The experiences of low-income families. New York, NY: Community Service Society of New York.

Appendix 1

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Family Support Survey

The first set of questions relates to agency and budget information.

1. In what fiscal year did your agency begin to provide family support services funded by the Department of Mental Retardation?_____

2. Through which Department of Mental Retardation region is your family support service provided? *(Please check all that apply.)*

_____Western
_____Central
_____Northeastern
_____Southeastern
_____Metro

3. What is your agency's total operating budget from the Department of Mental Retardation for the previous fiscal year? (*FY'97*) $_____

4. What is your agency's total annual amount for family support services? *(FY'97)* $_____

The next set of questions relates to those families you support.

5. In FY'97, please indicate the number of families who received family support from your agency based on the age of the person with a disability.

_____0-3 years old
_____4-22 years old
_____23-55 years old
_____56+ years old

6. Does your agency maintain a waiting list for family support services?

_____Yes
_____ No *(If no, skip to question 7.)*

6a. If **yes**, in FY'97, what was the <u>average</u> number of families per month on a wait list for family support services from your agency? _____

6b. If **yes**, does your program provide any assistance to families who are waiting for services?

_____Yes
_____No

6c. If **yes**, please check all that apply.

_____Distribute brochure/newsletter
_____Referral to other sources of assistance (SSI, elder services)
_____Referral to other family support agencies
_____Training and conference information
_____Fact sheets
_____Resource directories
_____Educational advocacy
_____Other (please specify)_____

7. Who has responsibility for determining eligibility for family support services? *(Please check all that apply.)*

_____DMR Area Director/Assistant Area Director
_____DMR Clinical Director
_____DMR Chapter 688 Coordinator
_____DMR Service Coordinator/Case Manager
_____Family Council
_____Family Support Director/Family Support Staff
_____Consumer
_____Family Member
_____Other (please specify)_____

8. Who has responsibility for determining who receives family support services? *(Please select all that apply.)*

_____DMR Area Director/Assistant Area Director
_____DMR Clinical Director
_____DMR Children's Coordinator
_____DMR Chapter 688 Coordinator
_____DMR Service Coordinator/Case Manager
_____Family Council
_____Family Support Director/Family Support Staff
_____Consumer
_____Family Member
_____Other (please specify)_____

9. On what basis are families selected for receiving services through this program? *(Please select all that apply.)*

_____All families who are found eligible receive services.
_____First come, first served.
_____Random selection (e.g., a lottery).
_____Selection based on the intensity of a family's needs.
_____DMR request.
_____Other (specify) _____

This next set of questions relate to family support services and assistance received.

10. What family support services were <u>provided or paid for by your agency</u> in 1994 and 1997. *(Please mark each category that applies.)*

TYPE OF SERVICE	SERVICE PROVIDED OR PAID FOR BY AGENCY			
	1994		1997	
	YES	NO	YES	NO
Adaptive Equipment				
Behavioral Management				
Case Management				
Child Care				
Computers				
Counseling (therapeutic)				
Educational Advocacy				
Generic Services				
Health Insurance and Medical Expenses				
Homemaker				
Home or Vehicle Modifications				
Household Expenses (rent, utilities)				
Homemaker				
Information and Referral				
Intensive Case Management				
Legislative Advocacy				
PCA Case Management				
Recreation/Leisure (camps, vacations)				
Recruitment/Training of Respite Providers				
Facility-Based Respite				

TYPE OF SERVICE	SERVICE PROVIDED OR PAID FOR BY AGENCY			
	1994		1997	
	YES	NO	YES	NO
In-Home Respite				
Out of Home Respite				
Sibling Support				
Skills Training				
Specialized Therapies (physical occupational, speech)				
Support Groups				
Training/Conferences				
Transportation				
Other (please specify)				

11. In a crisis, are supports available within 24 hours?

_____Yes
_____No *(If no, skip to question 12.)*

11a. If **yes**, please describe some of the supports.

_____
_____

11b. If **yes**, how frequent is the occurrence of a crisis? (*Please select one.*)

_____The program handles a crisis case infrequently (less than once a month).
_____The program handles a crisis case once a month.
_____The program handles a crisis case once a week.
_____The program handles a crisis case daily.
_____Other (please specify)_____

12. Who is responsible for the resolution of a complaint regarding services?
(*If this is a team, please list all participants by job title.*)

_____
_____
_____

This next set of questions relates to system changes in the delivery of family support services.

13. Have funding levels changed in your agency over the past three years? *(Please select one.)*

_____Funding has steadily increased every year (over 25%).
_____Funding has increased slightly every year (10-25%).
_____Funding has remained fixed at the same level.
_____Funding has diminished slightly every year (10-25%).
_____Funding has significantly been reduced every year (over 25%).

14. Has the philosophy of family support changed in your agency in the past five years?

_____Yes
_____No

14a. If **yes**, please describe the changes.

_____
_____

15. Has the program modified or expanded technical tools. *(Please check all that apply.)*

_____E-mail access for families
_____Computer upgrades and improvements
_____Adaptive equipment improvements (i.e. TTY)
_____Voice mailboxes
_____Fax access for families
_____Pager access for families
_____Cell-phone access for families
_____Web sites
_____Other (please specify)_____

16. Has your family support agency changed any organizational practices in the last five years? *(Please check all that apply.)*

_____Rewritten job descriptions
_____Revised pre-service and in-service training curriculum
_____Revised hiring qualifications
_____Revised program brochure
_____Recruited new board members
_____Other (please specify)_____

17. Have the methods for funding family services and supports changed since 1994? *(Please mark each category that has changed.)*

FUNDING MECHANISMS AVAILABLE TO FAMILIES	**AVAILABLE IN 1994**		**AVAILABLE IN 1997**	
	YES	**NO**	**YES**	**NO**
Agency Managed				
Reimbursements with Receipts				
Direct Payment to Other Agencies Upon Family Request				
Stipends				
Other (please specify)				

This next set of questions relates to information on family control.

18. Are families included in determining how family support dollars are used?

_____Yes
_____No

18a. If **yes**, please explain.

_____
_____
_____

19. Does your agency have a family support council?

_____Yes
_____No

19a. If **yes**, can you describe their responsibilities/activities?

_____
_____
_____

20. Do you have mechanisms to involve family members in guiding program decisions and activities? (*Please check all that apply.*)

_____Families choose who or what support person will actually provide the services.
_____Families have access to their records.
_____Meetings are scheduled at times and locations that are convenient to families
_____Families have a say in how resources are used for their own family.
_____Families complete satisfaction surveys on an annual basis.
_____Other (please specify)_____

21. Do you have mechanisms to involve family members in policymaking or planning, program implementation, and program revision? *(Please check all that apply.)*

_____Family members can attend meetings that pertain to overall operations of the program.
_____Families are involved in developing the menu of service options available.
_____Other (please specify)_____

22. What percentage of families are participating in family directed projects including family councils, family training institutes, and family leadership activities?_____%

23. To what extent does the agency make accommodations to include all families? *(Please check all that apply.)*

_____Information is available in a variety of languages.
_____Services and supports are offered in convenient locations.
_____Agency offers flexible scheduling for meetings.
_____Agency provides access to transportation.
_____Agency provides child care.
_____Program staff represent different cultures and speak other languages.
_____Other (Please specify)_____
_____
_____
_____

This last set of questions relates to the general status of your family support agency.

24. What compliment is heard most often about your family support program?

_____
_____
_____

25. What complaint is heard most often about your family support program?

_____
_____
_____

26. What barriers prevent your program from delivering services and supports? *(Please check all that apply.)*

_____New DMR eligibility criteria
_____Funding
_____Community acceptance
_____Other (please specify) _____

27. What actions do you think need to be taken in the Commonwealth to further enhance the services and supports that are offered to families caring for a family member with disabilities?

_____
_____
_____

28. What positive actions from the Commonwealth have helped to improve and strengthen the provision of family supports?

_____
_____
_____

Thank you for completing this questionnaire. Please mail your response in the enclosed envelope. You may also fax your response to 617-727-0887.